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ORIGINAL REPORT

PARTICIPATION AND INTEGRATION FROM THE PERSPECTIVE OF PERSONS WITH SPINAL CORD INJURY FROM FIVE EUROPEAN COUNTRIES

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Objective: **To examine the subjective understanding of participation and integration of persons with spinal cord injuries from 5 European countries and to compare these findings with the International Classification of Functioning, Disability and Health (ICF)'s conceptualization of participation.**

Methods: **Semi-structured interviews with 54 persons with acquired spinal cord injuries and 3 with spina bifida from 5 countries were examined using qualitative content analysis.**

Results: **Integration was most often associated with social acceptance and, furthermore, with ordinary performance, equality and freedom of choice. Participation was most often described as ordinary performance, with less emphasis on social acceptance and equality. However, participation and integration overlapped in people's narratives and were difficult to separate. The perception of participation and integration was largely similar across countries. In contrast to others, however, Finnish interviewees were more likely to associate participation with contributing to society. A variety of life domains was identified, of which recreation and leisure, work life, sports and going out were the most prevalent.**

Conclusion: **While participation domains are well covered by the ICF, as is the notion of ordinary performance, interviewees also referred to a rights (e.g. acceptance) and duties (e.g. contribution) perspective.**

Key words: social participation; community integration; spinal injuries; qualitative research.

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INTRODUCTION

Participation and integration are major outcomes of medical rehabilitation of persons with health conditions such as spinal cord injury (SCI). Participation is understood as "involvement in life situations" and is considered a key component of human functioning, as described in the International Classification of Functioning, Disability and Health (ICF) (1, 2). Moreover, full and equal participation in society of persons with disabilities is acknowledged as a pivotal human right (3).

Numerous instruments have been developed to measure participation, many of which are based conceptually on the ICF (4–8). However, despite apparently clear and comprehensive lists of categories, the ICF's definition of participation as "involvement in a life situation" neither specifies how participation relates to other concepts, such as social integration, nor does it clarify what participation restrictions actually mean to persons with disabilities (9). Against this background, several qualitative studies on persons' with disabilities' understanding of integration and participation have been undertaken and show that people's understanding of participation or integration often relates to more general and abstract concepts than are suggested by the ICF, such as autonomy or respect (10–16). Knowledge about the meaning of participation and integration to persons with disabilities is important, since people's subjective understanding will eventually guide their behaviours, aiming at optimizing participation and integration. Moreover, survey research may query people about barriers to participation, quality of participation, etc. Insights into the subjective comprehension of those concepts among people with disabilities will help us better to understand which cognitive representations such questions trigger. Our own previous study, conducted with persons with SCI living in Switzerland, found that participation was understood in terms of independence in living and decision-making and performing like persons without disabilities, while social integration involved additional aspects, such as acceptance by others (10). It may, however, be questioned if these findings are generalizable to other countries. At this time, no study has compared the subjective understanding of participation and integration across countries. An international sample may help to find commonalities and potential differences between countries to, for example, develop a measure of participation

and integration from the perspective of persons with disabilities that is applicable across countries.

This research was designed to compare the subjective understanding of participation and integration among persons with SCI from 5 European countries. In particular, the aims were to: (*i*) compare the subjective understanding of participation and integration; (*ii*) identify life domains associated with the concepts "participation" and "integration"; and (*iii*) discuss those findings in the light of ICF's conceptualization of participation.

METHODS

Design

A qualitative cross-national comparison based on content analysis of semi-structured interviews.

Sampling and recruitment

A purposive sample of persons with SCI was drawn from Finland (FI), Germany (DE), Ireland (IE), Northern Ireland (GB; further referred to with NI), and Switzerland (CH). The inclusion criteria were having an SCI or spina bifida (SB) for at least 3 years, and a minimum age of 18 years. Persons with SB were included as they were members of national SCI associations and SB is considered a congenital SCI (17). Persons with mental or cognitive impairments were excluded. Variation of the sample with respect to gender, age, paraplegia/tetraplegia and urban/rural area was established without pre-specified quota.

During the recruitment process SCI networks available to the researchers were employed. The snowball procedure (18) was used to complete the sampling. Peer counsellors from the Swiss Paraplegic Association contacted participants in Switzerland. In Finland, employees of a rehabilitation centre recruited participants who visited a specialized centre for SCI out-patient therapy. In Germany, participants were recruited through wheelchair sports clubs, disability organizations and the German Association of People with SCI. In the Irish Republic and Northern Ireland, board members of Spinal Injuries Ireland and Livability, respectively, recruited participants for the study. For the aims of the overall study project, interviewees were recruited from both the Irish Republic and Northern Ireland. Contacts with national associations of persons with SCI were facilitated through the European Spinal Cord Injury Federation (ESCIF).

Ethics

The study was performed according to the principles of the Declaration of Helsinki of the World Medical Association. Written informed consent was obtained from all participants. This study only included persons with SCI living in the community and not inpatients, therefore it was not eligible for submission to the medical ethics boards of the respective countries.

Interview scheme

A semi-structured interview guide (available from the corresponding author) was developed in English, validated in a pre-study and translated into German and Finnish, each by 2 authors whose mother tongue was the respective language. First, we asked the interviewee: "When we talk about a person with SCI participating in society, what do you think is meant by this?" (DE: *Wenn man sagt, dass jemand mit einer Rückenmarksverletzung an der Gesellschaft teilnimmt, was verstehen Sie darunter?*; FI: *Kun puhutaan selkäydinvammautuneen henkilön osallistumisesta yhteiskunnassa, niin mitä sillä sun mielestä tarkoitetaan?*; for Swiss interviews, questions were posed in Swiss German idiom on the basis of the German interview guide). Next, we asked the same question for "integration in society". Then we posed the question, whether "participation" and "integration" are the same for the interviewee. We continued by asking, whether s/he felt they were participating and were integrated in society, respectively. The interview proceeded with questions on perceived facilitators for, and barriers to, participation and integration. The interviewees were also asked which strategies they use to optimize participation and integration and, finally (with the exception of the persons with SB), to compare their perceived present participation and integration with their situation before the onset of SCI.

Data collection and management

The interviews were conducted face-to-face in English, Finnish, German and Swiss German, respectively, by the authors or students, who were all trained by the senior author. All interviews were audio-taped and transcribed verbatim before data analysis. The mean interviews length was 1 h. Data were managed with MaxQDA software (www.maxqda.com/).

Data analysis

In the first phase, interviews were analysed in the respective language using qualitative content analysis according to Mayring (19). Categories were created inductively and revised during coding for their reliability. To address different expressions in different languages the sense of the expressions that the interviewees used to describe participation and integration in society was compared with the sense of previously coded elements of understanding. New and head categories were created if appropriate. Approximately half of the interviews were coded by 2 researchers together, who were fluent in the respective language, the rest by 2 researchers independently and then compared. Differences were discussed in order to achieve consensus; and in difficult cases a third researcher was consulted. The respective sequences were translated into English if necessary. Finally, the categories were back-coupled and analysed quantitatively. The first author of this paper, who is fluent in all languages used in this study, was involved in all steps of the analyses of the different samples.

Elements, i.e. units of meaning in participants' accounts of participation and integration, respectively, were identified in: (*i*) direct answers to questions about interviewees' subjective understanding; (*ii*) interviewees' comparisons of their current participation and integration with the situation before onset of SCI; and (*iii*) when the interviewee explicitly referred to a subjective understanding by saying, for example, "For me, integration is…", or "…and in that sense I participate".

In the next phase, interviews were screened for domains, i.e. life spheres, associated with participation and integration. Subsequently, codes were linked to the ICF (1). Data were analysed in terms of the percentage of persons who mentioned them.

RESULTS

In total, 57 interviews were analysed (Table I). Three persons had SB (1 of whom sustained an additional traumatic SCI as an adult), the remainder sustained a traumatic SCI.

Subjective meaning of participation and integration

The identified meaningful elements related to interviewees' understanding of participation and integration are shown in Table II with sample quotations. Table III presents relative frequencies for those elements, as triggered by the terms participation vs integration, for the total sample and across countries.

Table I. *Sample description*

	Total (*n* = 57)	Switzerland (*n* = 13)	Finland (*n* = 15)	Germany (*n* = 16)	Ireland and Northern Ireland (*n* = 13)
Gender, *n*					
Male	39	5	12	12	10
Female	18	8	3	4	3
Age, years, mean (range)	44.8 (20–75)	49.2 (20–75)	36.7 (20–51)	49.5 (37–65)	43.9 (32–59)
Time since injury (SB excl.), years, mean (range)	19.2 (3–46)	18.5 (3–38)	15.9 (5–30)	22.0 (3–46)	20.3 (3–31)
Age at injury (SB excl.), years, mean (range)	25.8 (2–49)	34.6 (17–63)	21.3 (2–36)	27 (18–49)	22.2 (17–30)
SB	3	2		1	
Level of injury, *n*					
Paraplegic	36	11	4	13	8
Tetraplegic	21	2	11	3	5

SB: spina bifida.

Table II. *Elements referring to participation and integration*

Element	Description	Sample quotes*
Adaptation to society	Having adapted to other people, to terms of society	(I) That you have adapted well to the environment [where you live in] (*Riina*, FIN) (I) That you adapt to everyday life as good as possible (*Lasse*, FIN)
Autonomous functioning	To live independently or as independently as possible, and to do things by oneself instead of being dependent on others	(I) It's not trying to be more helped than is necessary (*Gerry*, NI) (I) That you're as independent as possible, and, if you can drive yourself, that you're able to get your chair in and out of the car and to travel wherever you want (*Aileen*, IR)
Being active	To be active, being «busy», having «full/filled» days, interviewee refers to specific activities and generally to «doing things» to underline how active s/he personally is.	(P/I) When I participate, actively, you know, it means automatically that I'm integrated in all that (*Beat*, CH) (P) I think I participate very much myself, socially, workwise, most definitely, and leisure, yeah, I'd say I would have a very busy and active life (*Sean*, IR)
Continuance	Having the pre-injury lifestyle and social roles as a reference for integration and/or participation without interviewer referring to pre-injury	[I feel integrated] to a certain extent, but I in one sense/ I used to be a roofer before my accident […] just in a matter of seconds taken out of the life I had […] the hardest thing I found about was to just finding something that I would be interested in again (*Ryan*, IR) Yes [I feel integrated]. I still have the same circle of friends as I did before (*Käthy*, CH)
Contribution	Being of use for and making a contribution to other people›s life and the society	(P) That you participate in societal activities, such as politics (*Janne*, FIN) (P) Participation is also active contribution, I'm for example involved in voluntary work (*Marko*, GER)
Equality	Having equal chances and rights with able-bodied people, not being or feeling discriminated against	(I) When I can talk about equality, that's for me integration (*Thomas*, CH) (I) Integration means simply that everyone is equal, so I don't see why we should demand any special conditions (*Birgit*, GER)
Feeling of belonging	Feeling being part of society; to feel belonging to something	(I) [Integration is] how you participate, the way you're part of society, it's belonging to something (*Heikki*, FIN) (I) [Integration is] belonging, feeling like a group together (*David*, CH)
Freedom of choice	To do and to have the choice to do what you want, participating according to your interests	(P) I'm completely free to do what I want, to participate or not to participate. My job I've also arranged so that I can do it when I want (*Heikki*, FIN) (I) I feel I'm a part of everything that goes on, so as much as I want to be or not want to be, so yeah, the choice is there, I feel I participate (*Esther*, IR)
Inclusion	Interviewee compares and/or equals «integration» with «inclusion»	(I) By integration I understand that people from other countries are (to be) integrated. Inclusion in turn is the new term and means that people, who are hampered by their disabilities, are (to be) included in society (*Sylvia*, GER) (I) Integration, inclusion, the term inclusion is used, or now here integration (*Thorsten*, GER)
Ordinary performance	To do what other people do, leading a normal lifestyle; «doing normal» and not withdrawing	(I) I go and do out there like all other ramblers, so yes, I feel integrated (*Heli*, FIN) (P) I think it's the same with everybody. […] so there's not much that I'd do that other people don't do. It's pretty much the same (*Aileen*, IR)
Social acceptance	Being accepted by others, seen as a person and not as a wheelchair-user, regarded as a full member of society; not being excluded	(I) Just being accepted in general within (*Erin*, NI) (I) When you know that most people take you as you are, although sitting in a wheelchair (*Cemal*, GER)
Socializing	Emphasizing socializing with other people, and the importance of meeting and being in contact with friends etc., joining people, particularly the able-bodied population	(I) I go out and meet people, I talk to people. […] I'm just there and make something with people I like, meet new people, even in the office here, I meet new people every day. You know so, I think I integrate well enough (*Owen*, IR) (P) Participating […] also socially, in social activities, whatever the person is interested in […] that you go and join the healthy people […] that's for me integration (*Matti*, FIN)
Subjective perspective	Interviewee says, integration/participation is a subjective issue, perceived quality of life, or feeling satisfied	(P) [I feel participating] from sex to sport, my quality of life rocks (*Thorsten*, GER) (P) I think every individual just generally has a different term of integration, whether they're in the wheelchair or not (*Aaron*, NI)

*P: quote relates to a particular question on participation; I: quote relates to a particular question on integration.

Table III. *Elements of participation and integration in total and across countries*

	Total ($n=57$)		Switzerland ($n=13$)		Finland ($n=15$)		Germany ($n=16$)		Ireland and Northern Ireland ($n=13$)	
% of the sample	P	I	P	I	P	I	P	I	P	I
Ordinary performance	58	53	62	62	53	67	63	44	54	38
Not withdrawing	14	11	8	15	20	27	13	0	15	0
Social acceptance	25	75	31	69	13	53	44	100	8	77
Not being excluded	11	26	15	0	7	20	13	50	8	31
Equality	9	37	8	46	7	27	19	31	0	46
Autonomous functioning	21	16	38	23	7	7	13	6	31	31
Freedom of choice	35	28	38	31	20	20	25	13	62	62
Socializing	23	18	38	38	27	13	6	6	23	15
Contribution	28	14	8	23	80	13	19	19	0	0
Feeling of belonging	5	21	0	31	13	27	0	13	8	15
Continuance	9	19	23	46	7	13	0	6	8	15
Subjective perspective	9	18	0	15	0	13	13	13	23	31
Being active	14	0	23	0	7	0	6	0	23	0
Adaptation to society	4	11	0	8	13	33	0	0	0	0
Inclusion	0	5	0	0	0	7	0	13	0	0
Key	0%		1–33%		34–66%		67–100%			

P: participation; I: integration.

In general, participation and integration in people's narratives seemed to overlap and were difficult to separate. Some participants stated: "I can separate it in my mind, but not in words." (*Esther*, IE). For example:

> *Interviewer:* Is participation and integration the same for you?
>
> *Matti:* Yes. Because, when you participate, you're adapted, integrated into society, at least to some extent.
>
> *Interviewer:* We may then speak about participation only.
>
> *Matti:* No, no, no. I wouldn't say *absolutely*, of course not, but let's say they [who participate] are mainly a *part* of the society.
>
> *Interviewer:* So you see a difference between the two…?
>
> *Matti:* Yes, they're definitely not the same. How can I describe what I mean. When you're integrated, you're *part* of the society, and being part of the society is exactly being there, among people, and participating in others' lives. (*Matti*, FI)

The most prevalent elements related to participation across countries were ordinary performance, freedom of choice, and contribution, while integration was most frequently described in terms of social acceptance, followed by ordinary performance, equality, freedom of choice, and not being excluded.

The element of being active was only used to illustrate participation, and contribution, autonomous functioning, and socializing were somewhat more related to participation than to integration.

Integration seemed more often than participation to refer to a societal perspective, in particular in terms of social acceptance and equality, i.e. being "taken as a full member of society." (*Maria, CH*). *Dylan* (NI) felt that "integration is the quality of your participation. […] you are involved not only as a participant, you are involved as a person of influence or even a decision maker." People felt that integration was a matter of not only individual, but societal efforts, i.e. "there is something put in place to *allow* this person to become part of the society or what's going on." (*Esther*, IE).

Similarly, integration was more often associated with a feeling of belonging to society and not being excluded.

> "I now sit in the middle of the theatre, next to my friends and family or partner. And that's integration. Participation is getting into the theatre. Integration is being a normal, or as normal member of the audience." (*Dylan*, NI)

The element of not being excluded did not occur in the Swiss sample and was emphasized in particular by German study participants. Adaptation to terms of environment and society was somewhat prominent in Finnish participants' perceptions of integration, but not so in the other countries, while Swiss participants often referred to a sense of continuity between their current life and their life before the injury to illustrate the meaning of integration. That integration, and participation, is something that depends on subjective perceptions and feelings was mentioned by 4 participants from Ireland and Northern Ireland. Some Swiss and German participants thought negatively about integration, as the term was associated with a person who lacks social acceptance and equal rights:

> "I can't imagine that a non-disabled German would have any thoughts about his social integration. […] To be honest, someone without a disability, would he ask himself if he's integrated or not?" (*Max*, DE)
>
> "I mean, before [the injury] you don't pose the question of integration, do you? Why should I have been excluded before? Yes, the opposite of integration is being excluded." (*Susanne*, CH)

Notably, 80% of the Finnish participants described participation in terms of contribution to society. Interestingly, contribution to society was not mentioned by any of the participants from the Irish Republic or Northern Ireland. They, in turn, related both participation and integration more to freedom of choice than participants from other countries. While in the other samples social acceptance was the main feature of integration, among the Finnish interviewees the main feature was ordinary performance, particularly not withdrawing oneself.

Some participants brought up the term inclusion in relation to integration.

Domains of participation and integration

All study participants referred to domains in Community, social and civic life (ICF; Chapter 9), and all but 1 to domains in Recreation and Leisure (d920) (Table IV). These domains were brought up in various ways, e.g. to compare perceived acceptance in different domains, to illustrate how "normal" s/he regards his/her performance compared with people without a disability, or to compare present domains and personal interests with those before the onset of SCI.

Fifty-two persons spoke of participation and integration in terms of work and employment and 45 in terms of sports. Going out to restaurants and bars was referred to by 41 persons. More than half of the interviewees mentioned relationships with friends and family, arts and culture, holiday and travelling, associations, education, and shopping. Going out and shopping were often used to illustrate accessibility issues and social acceptance, as well as freedom of choice.

> "If I want to go out to a night club or whatever, I have to rely on friends help me into bed which isn't ideal. […] Having to rely on other people hampers my integration to a certain extent." (*Aaron*, NI)

Work was often referred to as "the norm", as an area for discrimination, or to illustrate restrictive social security policies for labour market integration:

> "[Participation is] working, like everybody else does." (*Lasse*, FI)
>
> "My boss had welcomed it [re-integration]. But after 6 months he suddenly refused. […] The reason was, if he had employed me, it would have been difficult to dismiss me in case." (*Michael*, DE)

Instead of specific activities, the interviewees often referred to life spheres in a sense of living life. Domestic life, for example, was often brought up in discussing living on one's own instead of in a nursing home to highlight freedom of choice and autonomous functioning.

Interviewees from different countries emphasized different domains (Table IV).

When talking about participation and integration, sport was a less prominent domain in the sample from Ireland and Northern Ireland than in the samples from other countries. They were, in turn, more likely to refer to going out into restaurants and bars, which may reflect the traditional Irish pub culture. In the German sample, cultural domains, such as theatre and cinema, were more prominent than in the other samples. Finnish and German interviewees were more likely to talk about disability advocacy and other associations, and political life. In the Finnish sample, holidays and travelling, and, somewhat also, intimate relationships, were less prominent than in the other samples. Swiss and German study participants were likely to relate participation and integration to intimate relationships.

Table IV. *Domains of participation and integration, linked to ICF*

% of the sample	Total ($n=57$)	Switzerland ($n=13$)	Finland ($n=15$)	Germany ($n=16$)	Ireland and Northern Ireland ($n=13$)
Domestic life (Chapter 6)	91	100	87	88	92
Shopping (d6200)	58	69	60	44	62
Other specified (d698)	49	38	27	63	69
Unspecified (d699)	44	0	53	56	62
Interpersonal interactions (Chapter 7)	96	100	93	94	100
Friends (d7500)	60	77	53	50	62
SCI-peers (d7504)	35	0	33	56	46
Family (d760)	53	38	47	56	69
Intimate relationships (d770)	49	62	33	63	46
Major life areas (Chapter 8)	95	85	93	100	100
Education (d810–d839)	58	62	60	50	62
Work and employment (d840–d859)	91	77	93	100	92
Community, social and civic life (Chapter 9)	100	100	100	100	100
Associations (d910)	58	46	80	69	31
Political life (d950)	37	15	73	25	31
Sports (d9201)	79	85	80	94	54
Culture (d9202)	60	46	53	81	54
Hobbies (d9202–d9204)	37	46	60	19	23
To go out (d9205)	72	62	67	69	92
Formal and informal events (d9208)	30	15	40	38	23
Holiday and travelling (d9208)	60	69	33	75	62
Outdoor activities (d9208)	42	46	53	31	38
Human rights (d940)	11	0	13	19	8
Unspecified (d999)	79	92	73	69	85

Key 0% | 1–33% | 34–66% | 67–100%

ICF: International Classification of Functioning, Disability and Health.

Being in public was frequently referred to without specifying any particular domain (in terms of ICF, Community, social and civic life, unspecified). In contrast to the private sphere, being in public was also seen as a means to positively influence other people's attitudes in terms of integration and participation of people with SCI in general[1].

DISCUSSION

This study examined subjective understanding of participation and integration among persons with SCI from 5 European countries. While many participants used the terms participation and integration in an inconsistent manner, some basic differences were obvious from the interviewees' associations with the 2 terms. Across countries, the term "participation" more frequently referred to (ordinary) performance in specific activities, whereas integration more often included a societal perspective, particularly in terms of social acceptance and equality, i.e. being regarded as an equal member of society.

Some of the coded elements of participation and integration appeared to be overlapping or complementary to each other. For example, being able to perform activities, that anybody else does, necessitates adequate conditions offered by the society, i.e. social acceptance on a societal level. On the other hand, being active may be a means to engage with other people and thereby foster their acceptance (12, 13, 20). Simplifying, we could say participation is what you do to experience integration. Interestingly, the perception of participation by our participants came close to the way participation is categorized in the ICF, i.e. as specific activities and situations, whereas integration appears partly supplementary to the ICF (13, 21, 22).

In general, integration appeared to be the broader term and there was more agreement regarding its meaning across countries. Surprisingly, there were only few pronounced differences between countries. For example, Finnish interviewees perceived contribution to society as a main feature of participation, while Irish and Northern Irish interviewees had a somewhat more individualistic notion of participation and integration, emphasizing activity and autonomous functioning. In a qualitative study with relatively small samples it is, however, difficult to disentangle to what degree cross-country differences are due to: (*i*) semantics vs (*ii*) national differences in social and economic policies intending to "integrate" those with a disability vs (*iii*) general cultural values, such as an ethos of primarily pursuing individual goals, as opposed to contributing to the larger society as one's primary responsibility, with or without disability vs (*iv*) differences in the composition of individual situations within the samples. Larger and more representative samples including people without disabilities are needed to further elucidate this question.

[1]Ruoranen K, et al. Strategies for participation in society from the perspective of persons with spinal cord injury: a qualitative study from six European countries. Submitted to European Journal of Disability Research (February 2014).

The present comparative study continues the picture from our previous study in Switzerland (10). However, an understanding of participation and integration in terms of an individual's contribution to society became more important with the inclusion of additional country samples. Previous work has reported autonomy, contribution, normality, equality and socializing to be central features of participation and integration from the perspective of people with disabilities, and this was confirmed in our study (11–14, 22, 23).

Various studies have reported the relevance of relationships and work life for participation, life satisfaction and quality of life of people with severe injuries. While relationships with friends, family and partners are broadly experienced as satisfying, work life appears a problematic domain because of unmet needs (24–28). This was similar in our interviewees. Often domains were used to exemplify accessibility issues, or to convey where the person experiences full acceptance or freedom of choice.

Feelings and experiences, i.e. subjective perspectives of the person who is "involved in a life situation", are missing in the ICF's definition of participation. They may, however, be viewed as an additional qualifier for restrictions or problems in participation from the perspective of persons with a health condition. Then, a problem, e.g. in forming a relationship (d7200), could be qualified by a person's feeling of being accepted in it, in contrast to an objective perspective of a person's ability to form interactions "in a contextually and socially appropriate manner" (1). We could think of a qualifier for "getting respect", mainly applicable for the categories of Chapters 8 and 9, and test, whether it varies across countries. While the elements could be used to qualify specific domains, they may also be employed to assess the quality of overall participation from the perspective of persons with disabilities. Integration could then be seen as a goal depending on levels of perceived participation restrictions. As our study participant Dylan put it "Integration is the quality of your participation".

Domains of participation and integration identified in this study could well be linked to categories of the ICF activities and participation component. These, however, mainly covered chapters 6–9. The ICF offers 4 different options for distinguishing between participation and activity, the first of which is to treat some chapters as activities and others as participation (without overlap). Our findings support this first option. However, we cannot exclude that we may have primed study participants towards that direction by using the term society ("participation in society") in our entry question.

Study limitations

This study has several limitations. The selection of countries, as well as the recruitment procedure, were based on convenience, which may have led to inclusion of countries within which persons with SCI are sensitized to the research topic, e.g. by interacting with the same international associations. Also, demographic and SCI-related differences between country samples may have reduced inter-country comparability. Future studies may address the latter potential source of bias by employing larger samples. However, in spite of differences in

compositions of samples, the similarities are striking. Three participants with SB lacked pre-SCI experience, which may have biased the results. Further research is needed into whether people with congenital SCI emphasize different aspects of participation and integration from people with long-term traumatic SCI. Imprecise translations are an additional source of potential bias, although multi-lingual researchers were involved in order to minimize this.

Conclusion

Overall, shared views prevailed in this study, particularly with respect to the term integration. While domains of participation and integration are well covered by the ICF, as well as the notion of ordinary performance, interviewees also referred to a rights (e.g. acceptance) and duties (e.g. contribution) perspective. These findings may enhance our understanding of how participation in different domains may be qualified and what restrictions on, and facilitators to, participation may actually mean for persons with disabilities.

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